WANTED! – Virtual Coach for People with Thorny Diseases

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Abstract

The main objective of this study was to propose a concept for a virtual coach to be used by people who suffer from costly and challenging diseases such as dementia, depression, diabetes and cardiac related issues, and by their caretakers presenting healthcare service providers or family members of the people suffering from the named diseases. Those listed diseases form almost an unbearable burden for individual persons, their next-of-kin, and those providing health services. The construction of the concept was based on earlier knowledge, and guidelines proposed for design science research were applied. The proposed concept is to sketch a virtual coach that utilizes sensor-based data and written diaries, and that helps patients and their caretakers to get accurate and individual information to support everyday life and healthcare.

1. Introduction

The motivation for the study raised from the high global burden of dementia, depression, diabetes, and cardiovascular disease (CVD), as traditional models of healthcare appear not sufficient to manage these prevalent chronic diseases among ageing population (see e.g. [1]). The authors strongly believe that the use of an information and communication technology (ICT) based virtual coach can enable more detailed, objective, and real-time monitoring, and encourage patients to commit to given advice. As such, it can substantially contribute to reduce problems and challenges related to managing such critical diseases as perceived by the individuals suffering from the diseases and their caretakers.

This should also be seen in the light of current societal trends and developments, where ICT solutions are increasingly used for the provision of care. For example, in Sweden the company Kry is offering on-line doctor appointments[1]. This is just one of many shifts towards a digitalization of care, which indicate that a virtual coach for the care of people with for example chronic conditions are both timely and feasible.

The constantly growing number of elderly people presents a significant challenge for the healthcare sector by increasing demand for medical care and putting a sizeable pressure on national budgets. Clark et al. [2] pointed out the highly potential risk for health decline and loss of independence and argued that lifestyle interventions offer potential for reducing such negative outcomes. The current study responds to their arguments and concerns.

Healthcare spending in the European Union is expected to reach up to 10.6% of GDP by 2060, and continuous health care spending growth is also predicted in the United States of America and Canada with respective projections for 2018 at 17.9 % and 11.6 % [3]. According to the WHO, more than half of this spending goes to chronic disease treatment [4].

Depression is often correlated with health challenges as suicide, loss of productivity, social isolation, alcohol abuse, somatic comorbidities, and stigma [5]. At the European level, depression costs about 92 billion euros and influences 30 million EU citizens per year. Dementia is among the top causes for disabilities in later years and is one of the biggest global public health and social care challenges facing people today and in the future. In 2015, the estimated global cost of caring for people with dementia was US $ 818 billion, and it is expected to become a trillion-dollar disease by 2018 [6]. The American Diabetes Association (Association) released new research on March 6, 2013 estimated the

[1] https://kry.se/en/

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total costs of diagnosed diabetes have risen to $245 billion in 2012 from $174 billion in 2007. This figure represents a 41 percent increase over a five-year period. Having diabetes is associated with substantially higher lifetime medical expenditures despite being associated with reduced life expectancy. If prevention costs can be kept sufficiently low, diabetes prevention may lead to a reduction in long-term medical costs [7].

Cardiovascular disease (CVD) is one of the leading causes of global mortality and morbidity, and is responsible for an estimated 16.7 million deaths worldwide (30% of all deaths). CVD also represents a major economic burden on health care systems in terms of direct (e.g., hospitalizations, rehabilitation services, physician visits, drugs) and indirect costs associated with mortality and morbidity (e.g., losses of productivity due to premature mortality and short- or long-term disability) [8,9].

Already in the 1990s, new ways to rehabilitate psychiatric patients were called, however many of them were silence due to organizational barriers, which raised a need for new kind of champions into healthcare [10]. We argue that a virtual coach will be a champion as a supplement to existing treatments in rehabilitating people with mental or other multiform disease that are chosen based on their burden to the people and healthcare, and the relationships of the diseases with each other as discussed in later sections.

The virtual coach may consist of tailored user data, adaptive interaction mechanisms, intelligent systems for optimal guidance and treatment, wearable device to for recording and monitoring of individual health parameters. Such tool is expected to be an important tool for all stakeholders involved in care and treatment of chronic patients with somatic and/or psychiatric conditions. (See [11])

The issue is that there are not enough health service providers and mental health workers, and yet there has never been a greater need for creativity and innovation in organizing and delivering mental health care [12]. There is a need for knowledge on how mobile sensor technology can support people with dementia, depression, diabetes, or cardiac-related issues to manage with their diseases and rehabilitate with minor institutionalized care in the form of a wholeness consisting of a platform, personalized health data, healthcare guidance, and personalized interaction between the users and caretakers.

This study aims to reveal how the emerging knowledge and understanding of new kinds of information systems based on new technology such as wearable sensors can be harnessed to produce improved healthcare and wellbeing, and give birth to new business opportunities. The gained knowledge will be applicable in several disciplines such as health informatics, big data analytics, machine learning, medicine, and housing.

To meet these potential objectives, a research question was posed: *What kind of virtual coach is needed to ease life of people suffering from costly chronic diseases?*

The research question was answered by applying design science research, and the guidelines introduced by Hevner et al. [13] were followed. Despite the output of the current study was not implemented into a functional system, the introduced concept might offer a comprehensive solution for those professionals who will utilize the concept and finally build an artefact to be used by individuals and their caretakers in rehabilitation and managing the diseases.

There is a need for advancements of the knowledge on how modern ICT, with the help of mobile sensor technology, can support people with thorny diseases to manage their diseases and rehabilitate with minor institutionalized care. In our approach, the enabling ICT is seen as a virtual coach (see Fig. 1) in the form of a wholeness consisting of a platform, personalized health data collected by, for example, wearable sensors, interactive sessions, electronic diaries, open source data, healthcare guidance, and personalized interaction between the users and caretakers.

This study advances existing knowledge on wearable technology connected with different diseases, though having often relationships. The study produced a concept for a virtual coach that enables proactive support to the targeted groups of people with dementia, depression, diabetes and cardiac-related diseases. Health-related data and interventions may be shared with the patients and their caretakers to achieve increased patient independence, involvement and empowerment.

The paper is structured as follows. Next, earlier knowledge related to the research area is presented. Then, the research approach is described, followed by an explanation of the output of the study, and a presentation of an outline of the solution. Finally, the objectives of the introduced concept is discussed.

2. Literature review

Emerging technology has led to new innovations related to health and wellbeing. In their study about robotics, general ICT, sensor technology, telemedicine, medication dispensing device and videogame as assistive technologies ICT researchers listed chronic diseases third as problems of the elderly people [14]. The other listed seven problems were dependent living, fall risk, dementia, social isolation, depression, pool well-being, and poor medication management.

On the other hand, health information technology has been available since 1990's [15], but only recent development of sensor-based information gathering allows real-time tracking of people living at home or assisted care [16]. In addition to individual-based information, also existing data registered from the environment can be used for other but its original purpose [17].

Sensor-based wearables produce valuable information to be used in healthcare and wellbeing. Recent development of technology offers both challenges and possibilities to utilize the sensors in an innovative way that enables service providers to build new device and multidisciplinary data to be collected and used in healthcare [18, 19]. There already is evidence that combining data from personal health or wellness devices with electronic medical records may provide tools for early interventions or preventive actions in the hands of healthcare [20]. The role of self-management is recognized in health care even if challenges still exist [21].

In addition, a recent study has shown that the share of aging people using mobile device is increasing [22]. As technology progresses, it is being increasingly adopted by the aged people. According to the recent studies, older adults constitute high percentage of the users of touchscreen based devices such as tablets and e-readers. Moreover, there is a large number of studies proving that senior people are very open to the use of healthy ageing technologies that will make them less dependent on others (e.g. [23, 24]), even if there are suspicious notes as well (see [25]).

Along with the new technology, the popularity of ICT-enabled gaming has raised attention [26, 27, 28]. In their literature review, Wattanasoontorn et al. [27] analyzed health games and identified children, the elderly and patients with defined diseases as the most important target groups of serious games.

Today, the wearable sensor market is one of the most rapidly growing area in consumer electronics, and their global market is estimated to reach 34 billion US dollars by 2020 and almost 70 billion US dollars by 2025 [29]. The remarkable progress in sensor development with improved memory and battery properties enables measurements of human physiology 24/7 without laboratory arrangements. For example, epileptic seizures were predicted based on heart rate variability by using conductance and other ways like skin potential or admittance [30], and Parkinsons disease has been detected by accelerometers, gyroscopes and magnetometers [31].

Prior studies have also revealed that new sensor-based technology is recognized as a considerable aid for assessment of severity of symptoms in depression [32, 33]. Specifically, earlier studies have recognized relationships between depression and diabetes [34], dementia [35], and cardiac-related diseases [36, 37].

Current knowledge has revealed that the aging of populations is a global issue [38]. The amount of people aged 60 and over is predicted to increase in almost every country in the world during the period 2005–2050 [39]. In Europe, the healthcare policy makers are seeking for more effective ways to manage healthcare because nowadays 40 % of the public spending on health care is spent on people aged 65 years and over. In this spending, long-term care facilities form the most consuming [40].

Clark et al. [2] emphasized the importance of preventive and wellness care especially for older people and they proposed that interventions are cost-effective and applicable ways to increase wellness and physical and mental well-being, and at the same time reduce the emerging healthcare costs.

Furthermore, stress is a common problem experienced by people with dementia [41], and it is often related to expressions of symptoms such as apathy, aggression, sleep disturbances, wandering, and depression [42]. Statistics have also shown that 74% of family caregivers are concerned about maintaining their own health since becoming a caregiver, and 40% of caregivers report that the emotional stress of their role is high or very high [43].

Depression is the most predominant mental health problem among working-age patients. Depression in the workplace is a leading cause of lost work productivity, due to, for example, sick leave and early retirement. Lost productivity due to absenteeism and presentism represent over 50% of all costs worldwide related to depression [44, 45]. Early knowledge also reveals that means to manage and rehabilitate from depression vary and that not all depressed people prefer same kind of support and care [46].

In the U.S., nearly 3 billion dollars are used annually for seeking effective preventive actions against loss caused by the chronic diseases [47], and, for example, the role of interventions and prevention in the care of diabetes is outstanding [48]. Our proposed Virtual Coach is expected to reveal a functional solution to boost the preventive actions.

As verified by earlier research, the need to influence rehabilitating or managing chronic and costly diseases is evident. There already are proposals for solutions, e.g. multi-model sensor-based home environment for demented people [49]. However, so far there are only few if any research on solutions that are designed for multi-disease domain, e.g. presenting costly chronic diseases.

3. Research approach

As the topic is focusing on the near future, the study was based mainly on existing knowledge. In addition, suggestive empirical findings are presented to support the results. Existing knowledge was sought by applying a mapping study approach (see [50]). Design science research [13] was applied when sketching the virtual coach. Design science research leans on practice-related approach that includes best practices and several alternatives to evaluate the designed artefact [51, 52, 53].

Hevner et al. [13] offered guidelines for design science research and they were identified as follows: Guideline 1 about the design being an artifact was realized as a concept with written contents. Guideline 2 about problem relevance was realized with the knowledge that the costs of healthcare in these chronic diseases need solutions that are provided with the help of information systems and connected devices. Guideline 3 about utility, quality and efficacy of the design was responded with a theoretical evaluation by applying a descriptive evaluation method. Guideline 4 about research contributions was shown with the proposed concept that is viable. Guideline 5 about research rigor was followed by utilizing scientific literature review and performing the evaluation on top of earlier knowledge. Guideline 6 about search process was realized by analyzing earlier knowledge and seeking for the best solutions to meet the defined objectives. Finally, Guideline 7 was followed by writing a paper of the solution to be published in front of a scientific audience and to be further used by people who will implement the system and take it into function.

As the output was expected to be a concept for a virtual coach consisting of – among other parts – user-friendly and strongly personalized interfaces, several sensors collecting data, electronic diary, versatile interaction, efficient and productive algorithms, multidisciplinary knowledge was to be applied continuously. Specifically, to build a persuasive virtual coach, the factors of successful serious games [55] were to be noted in planning the interface.

4. Empirical study

The current study aimed to provide a concept for a Virtual Coach (see Fig. 1) to be used by individual persons suffering from defined long-term diseases and by caretakers who in collaboration with the main users aim to provide more productive healthcare and support for better wellbeing for the individuals suffering from chronic diseases. The study was to build on and advance existing knowledge on the use of wearable technology connected with personalized interfaces that inform and guide the users (patients and their caretakers) based on the individually collected health-related data, and on other data, e.g., open data from the environment.

Figure 1 illustrates that Virtual Coach has several functionalities. Individual persons with therapeutic relationship are monitored with wearable device according to their health status and as agreed with the healthcare. All patients are encouraged to write or speak to collect personal narrative to be analyzed. E.g. diabetics wear sensors to monitor their gait and they also measure glucose regularly. In addition to personal and individual data from wearables, Virtual Coach utilizes available open data e.g. about weather and air quality, and the data is analyzed and used to give beneficial information to the patients and their caretakers such as physicians and family members. As a solution, Virtual Coach has to be interactive via smart phones, tablets and laptops.

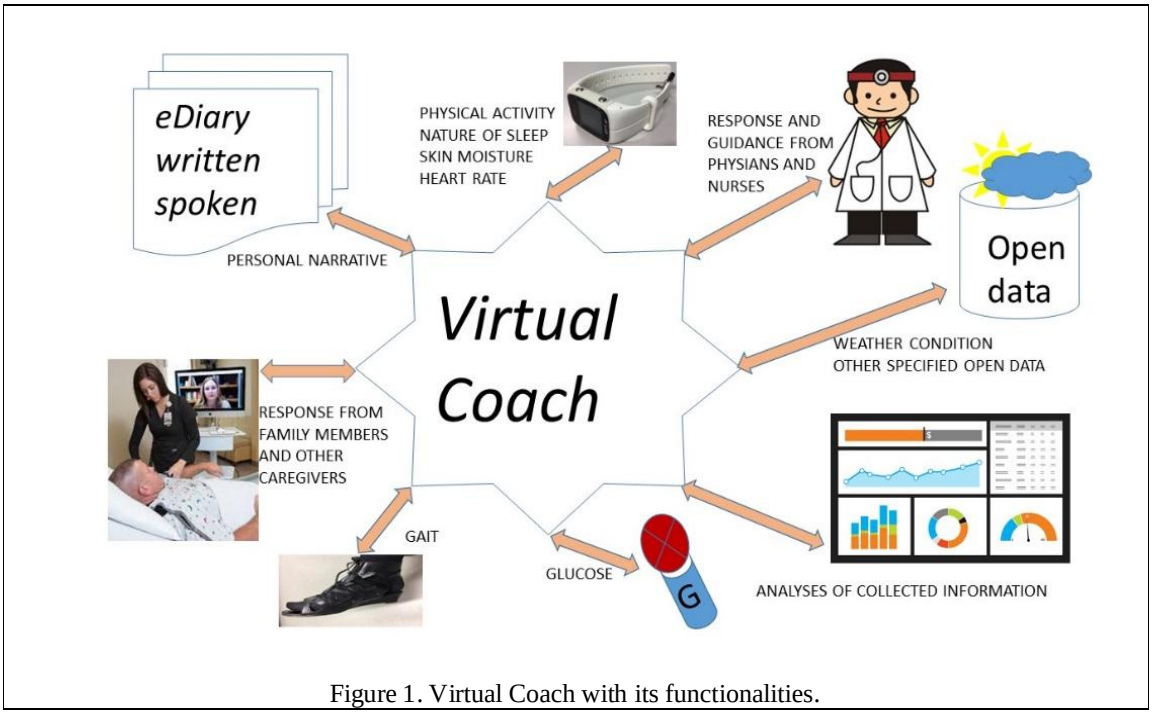

Figure 1. Virtual Coach with its functionalities.

Besides devices, Virtual Coach leans on efficient algorithms that produce user friendly information based on the collected data. Special emphasis is put on the interfaces that are tailored according to the user groups as the aim is to be a personal virtual coach that encourages and persuades the patients to follow given guidelines and assistance. Tailoring is needed to enable interfaces that support family members as next-of-kin to be empowered as well, and they are asked to write personal narratives, too.

First, the objectives for the Virtual Coach were defined. All together five objectives were identified: 1) Improve the wellbeing and health of aging people with diseases; 2) Increase the productivity of healthcare services; 3) Build chronic disease analytics model for sensor-based wearable data; 4) Build a concept for the virtual coach; and 5) Create ethical framework for the virtual coach.

Objective 1 was approached by identifying the diseases that were to be treated and managed with the help of the virtual coach. Dementia, depression, diabetes and cardiac-related diseases were chosen based on the costs and burden of these particular diseases. Then, wearable sensors to measure bio-signals such as acceleration, heart rate, heart rate variability, galvanic skin response, temperature and respiratory function were proposed to be included to get as descriptive information of the health as possible. In addition, glucose meters and sensors in soles were included in the design to be used by diabetics. Real-time data from the health will enable better scheduled treatments and consultations, and information for the patient about his/her real-time health status.

Objective 2 was approached by adding a design of mobile applications to be synchronized with sensor-based wearables and to be used by both the people suffering from the named diseases and their healthcare practitioners. With the real-time data, the applications were to provide encouragement, persuading messages, monitoring, activating hints, management and control, and to ensure informed and improved disease management and prevention in specified cases. The support for communication, for example by peers or in groups, was considered central for this objective.

Objective 3 was met by proposing a chronic disease analytics module separately for all diseases. The solution was to enable digitalization, integration, and effective use of big data related to the healthcare information of the patients. The data would include data from monitoring vital signs, notes from the physicians, prescriptions, laboratory data, pharmacy, and required administrative data. In addition, electronic patient records and emergency care data could be combined into the virtual coach. The idea was to build a holistic view of the patients' health information.

In addition to the analytics module, Objective 3 included a chronic disease health prediction module that was to monitor and record health and lifestyle data from the wearers of the sensors. The module was to be used

when designing personalized health models to support early detection of health changes.

Objective 4 included user-specific interfaces to enable interaction between the different stakeholders in parties who represented rehabilitation and management of the current diseases. In this context, user-specific interfaces meant that people suffering from e.g. diabetes had such features in the interface that spur the users to monitor their nutrition and physical activity adjusted to managing diabetes. As seen in Figure 1, there are devices such as glucose meter and sensors to analyze gait, and these two are specific for managing diabetes. On the other hand, people suffering from dementia are approached with interface that eases their everyday life and offers hints to remember. The virtual coach was to utilize available big data reporting, e.g. weather conditions and forecasts, temperature and location-based information to support awareness of the environment.

Objective 4 appeared to be the main objective as it was to realize the sections that were most visible for the users. Figure 1 illustrates how open data reporting e.g. weather conditions was included to add information that can influence the patients. Likewise, adding diaries into the system was to offer a tool to express thoughts and wishes. As the chosen disease domains differed from each other, there are also several disease specific features that were seen important to get the most benefit from the system.

Because the design of the interface was planned to be user-specific, the means of gamification were to be applied to build as user-friendly and engaging interface as possible. In case of long-term diseases, the role of motivation in applying given advice and support was to be supported with adding features that encourage users to return to the virtual coach frequently.

Objective 5 was about managing ethical issues and to build an ethical framework for such a virtual coach that was to be used by people suffering from long-term diseases. At the time of designing the virtual coach, there was only limited knowledge available and the need for ethical summary was identified.

In the study, the result was being realized as a theoretical model for a virtual coach that was designed to improve wellbeing and healthcare for people who suffer from dementia, depression, diabetes or cardiac-related disease. In addition, the role of healthcare professionals as users is crucial to get the planned functionalities with added interaction and self-care into action. However, a significant result in the study was expected to be new knowledge of online and virtual coach that utilizes sensors in managing chronic diseases. We believe that even if the current chosen domains consist of four defined diseases, the concept will be applicable for several other chronic or otherwise thorny diseases as well. At the time of the current study, there are no such solutions available, and thus existing scientific research in that area is humble.

5. Evaluation

According to Hevner et al. [13], the built artefact should be evaluated to ensure that it meets the requirement adjusted for it. They listed five ways to carry out the evaluation: observational, analytical, experimental, testing and descriptive methods. This section reports how the concept was evaluated by applying the descriptive approach.

Objective 1 was responded by identifying the diseases. Dementia, depression, diabetes and cardiac-related diseases were chosen in the focus because they have relationships with each other [32, 34, 35, 36] and due to their costs to the patients, their next-of-kin, and to the healthcare sector [4]. Then, wearable sensors to measure bio-signals were defined based on earlier knowledge (e.g. [32, 34]).

Objective 2 was targeted by mobile applications to be synchronized with the data collected by wearable sensors (see e.g. [22]). Additional emphasis was planned to note also the caregivers – especially next-of-kin – as statistics have revealed the increasing share of family members who get diagnosed with depression due to their burden or taking care of their near family members (see [43]). An additional proposal is also to form virtual care groups based on contextual parameters such as by analyzing communication patterns (see [54]).

Objective 3 was planned to lean on a solution that has to be built for analyzing data in each disease domain, using a novel combination of technologies such as dynamic group communication (see [54]), gamification mechanisms and multiple data analytics methods (machine learning, crowd-sourcing, etc.).

Objective 4 was met by designing several interfaces. The means of gamification were included to support the user activity and ease the use of the devices (see [55]). Special attention was paid to depressed people who often tend to get passive and withdraw (e.g. [42]). The onset of depression was also sought to be remedied by social functionality through dynamic group communication (see [54]).

Objective 5 was designed to notify and report any ethical issues that might emerge due to the sensitive data and health status of the users.

Finally, the evaluation phase acknowledged words of Hevner et al. [13] when they state that design science research results are informed in the knowledge base to be used by system building efforts. Therefore, a participatory stance was central, including users of the proposed system early in the design process through multi-disciplinary design workshops and focus groups

together with dedicated evaluation methods targeting design criteria such as ease of use.

6. Discussion

This study was to present a concept of a virtual coach to be used by people suffering from chronic diseases and by people taking care of those people. In this case, the caretakers can be family members or representatives of healthcare either in public sector or private sector.

In a recent report dementia, depression and chronic diseases were listed among the most significant reasons to seek new ICT tools to support elderly people in their everyday living [14]. The report encouraged other researchers to pay attention to design and develop assistive technology and to include caretakers and other stakeholders into the environment as using the technology. This is in line of the current study with its concept for the virtual coach.

The growing number of elderly people represents a significant challenge for the healthcare sector by increasing demand for medical care and putting significant pressure on national budgets [39, 40]. This study falls upon these issues by demonstrating how sensor-based virtual coach inspires people with most costly diseases to manage their wellbeing and to get motivated in caring of their health.

So far, effective sensor-based wearable technologies for monitoring, measuring, and managing chronic and costly diseases are not yet developed or evaluated for data accuracy and efficacy for health-care delivery and patient self-management or at least there is lack of published scientific studies of them.

Figure 2 illustrates the potential of Virtual Coach. In practice, the solution when implemented offers several possibilities for actors to benefit from the solution. One can assume that in the future more elderly live at home or home-like environments instead of in the premises of institutionalized organizations such as elderly homes or hospitals. Virtual Coach provides new means to offer support and healthcare into private homes if they are outfitted accordingly.

On top of those individuals who suffer from the defined chronic diseases, there are other stakeholders that may benefit from the solution. As illustrated in Figure 2, there are commercial partners such as insurance companies that could adjust their services according to the use of Virtual Coach.

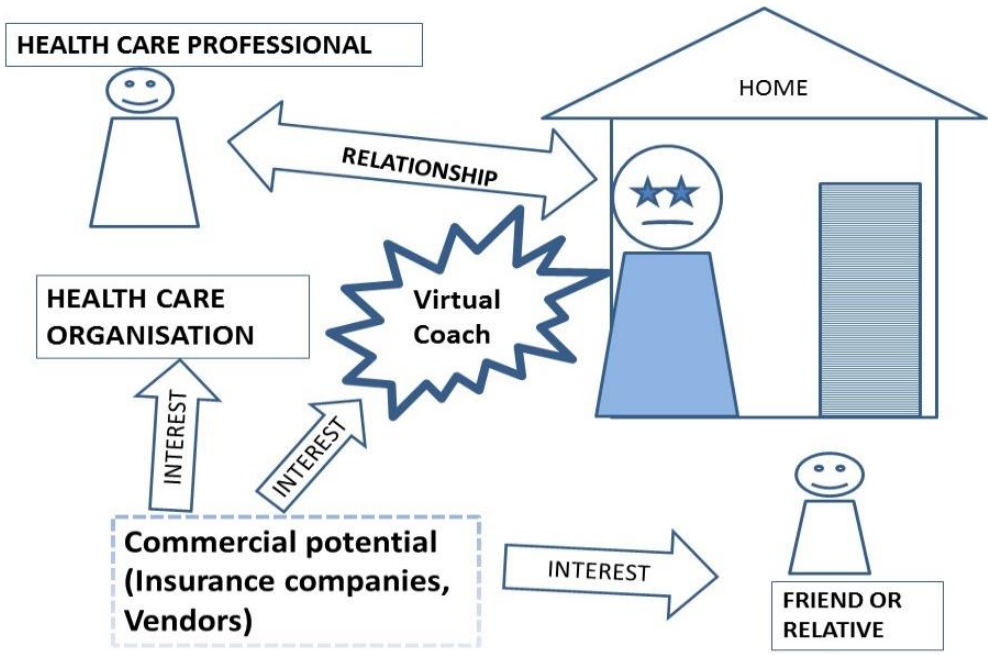

Figure 2. Virtual Coach in its environment.

Figure 2 also illustrates that the solution could be implemented in collaboration with several partners that can influence the content and functionalities of the Virtual Coach. For example, insurance companies can appreciate special functionalities and information that fits their business model, and vendors providing networking and connection could suggest functionalities that add both trust and effectiveness. However, in the beginning Figure 2 proposes that commercial potential is related to the productive and

effective care, and that it is reasonable to pay attention to this approach in future research.

As the result of the study, such a concept of a solution was described that it can be applied in several domains of chronic diseases. The result will have potential to foretell improvements of the efficiency at three levels (disease management, health management, and workflow management), and target many beneficiaries such as software developers, hospitals, healthcare practitioners, and patients suffering from dementia, depression, diabetes or major adverse cardiac events and those at risk.

The proposed concept of the virtual coach is applicable as the main way to carry out a preventive intervention (see also [2]). We argue that the virtual coach is able to produce positive activity among its users in the form of physical and mental exercise, added activity in writing and reading, and adding social activities among the patients. Especially the carefully designed interfaces that utilize means of gamification (see [55]) lure and persuade users to activities. This is in line with findings of Wattanasoontorn et al. [27] who identified patients with defined diseases as an important group of users. In the current concept for Virtual Coach, also caretakers and next-of-kin are considered as users who are supported by characteristics of gaming.

Moreover, the study returned a significant contribution to the body of knowledge adding to several disciplines such as computer science, human-computer interaction, information processing science, medicine, nursing science, process productivity, and public health. The study provided unique bases for advancing the knowledge on analysis of sensor information for developing proactive support to the targeted groups of people with dementia, depression, diabetes and major adverse cardiac events. It provided an analysis that presented a holistic view of the patient's health to be shared with the patients and their caretakers.

The research problem of the current study could also be answered in wider environments. In future studies, the designed virtual coach should be tested and evaluated in real environments among people of different age groups and in different disease domains. Furthermore, empirical and realistic experiences should be collected to find grounds for improving the output and to get information about the benefiters of the solution.

7. Conclusions

The main purpose of the study was to propose a concept for a virtual coach that would increase the wellness of people suffering from chronic diseases such as dementia, depression, diabetes and cardiac-related issues. One of the most valuable contributions is the understanding that there are possibilities to build solutions to be used by patients that suffer from distinct diseases that have weaker or stronger connections with each other. Even though these patient groups might not have much in common when it comes to care and rehabilitation, most of the functionality offered is based on similar design principles and to some extent overlapping sensor technology. In addition, patients often suffer from more than one of these conditions, which call for integrated health care solutions.

The study offered a concept for a virtual coach consisting of personalized data-based information, means for interaction, software to manage the system and its parts, a written or spoken e-Diary, and wearable device to collect individual data. Moreover, the solution allows additional device (glucose meter) to be connected and with its intelligent algorithms it provides the users with the relevant information. In addition to the patients and those at risk, the virtual coach will target several beneficiaries such as software developers, healthcare practitioners, and insurance companies.

The future will realize the concept as a Virtual Coach that in the hands of those suffering from thorny diseases will prove its benefits in several ways: it will offer real-time information to be used by physicians and other caretakers, and it will offer a tool that encourages people with chronic diseases to get support with the help of ICT-based solutions.

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